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The meaning of home when you don't live there anymore: Using body mapping with people with dementia in care homes

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Abstract

The significance of home is broadly recognised as representing selfhood, safety and autonomy. For older people, especially those with dementia, the ability to age in place at home can be threatened by a necessary move into a care home. Home has heightened importance for people with dementia. We know most people want to stay in their own homes, but there is limited research which explores what home means for people with dementia when they move into care homes. Based in a care home in regional New South Wales, Australia, this study used the arts-based method, body mapping, to explore what home meant to people with dementia and/or cognitive impairment. Seven body maps were co-created by current residents (four), family members and supporters (six) and researchers (three). The findings of the body-mapping process highlighted that home is much more than a physical location. Home meant having the ability to carry out practices and rituals, use objects, maintain relationships and experience sensations that are personally meaningful, and which differ from one person to the next. Their body maps revealed that in care homes, people could not 'do home' anymore because many of the practices, objects, people and places that mattered to them were no longer accessible. Body mapping was a useful method that facilitated the exploration of a holistic expression of home that would not have been possible with more traditional methods. For people with dementia, home was not only embodied and spatial, but also temporal, helping us to understand the ways in which care homes might facilitate a greater sense of home for people with dementia.

Keywords: dementia; cognitive impairment; embodiment; home; body mapping; care homes; care settings

Introduction

Home encompasses far more than what lies within the confines of a residence; it extends into communities, between people, and across space and time (Tolia-Kelly, 2004; Blunt, 2005; Blunt and Dowling, 2006; Gopinath *et al.*, 2018). Although its meaning is diverse (Blunt, 2005; Blunt and Dowling, 2006) and subjective (Robinson *et al.*, 2010), people frequently associate home with comfort and intimacy (Wallace *et al.*, 2012), identity (Blunt and Dowling, 2006; Gorman-Murray, 2006; Pilkey, 2013; Okafor, 2018), relationships (Ralph and Staeheli, 2011; Pilkey, 2013; Gorman-Murray, 2015; Okafor, 2018) and autonomy (Dyck *et al.*, 2005). Relations between individuals and home can shift over time, and over the lifecourse. The meaning of home then is unstable and transitory (Imrie, 2004: 747), influenced by dynamic experiences of gender, class, age and disability (Imrie, 2003, 2004).

Home is significant for people with dementia; the familiarity of home can create a sense of identity, selfhood and capacity (Gopinath *et al.*, 2018; Ward *et al.*, 2018). However, we also know that people with dementia may undertake a physical move into a care home as their support needs increase, and that with this the meaning of home may also change (Fleming *et al.*, 2015). So what does home mean for people with dementia who live in care homes? People with dementia often report that care homes do not feel like their real home (Robinson *et al.*, 2010; Nakrem *et al.*, 2013; Davison *et al.*, 2019; Nygaard *et al.*, 2020). Care homes occupy an ambiguous position as both public and private spaces (Nord, 2013; Buse and Twigg, 2014); there is a tension between the care home as a home for people with dementia and an institution and workplace (Nygaard *et al.*, 2020). Buse and Twigg's (2014) work on women wearing slippers and carrying handbags in care home lounges illustrates this; care homes are both places of ease and comfort (slippers) and also public display (handbags). Importantly, then, even though care homes are often not a home people with dementia would desire (Nakrem *et al.*, 2013), some people with dementia do talk about them as places where they feel safe in ways that they did not in their own homes anymore (Imrie, 2004; Nygaard *et al.*, 2020).

There have been increasing efforts to make care homes more homelike environments. In part, this is a result of an acknowledgement that environmental design – including the homelike qualities of care homes – can compensate for a person with dementia's changes in cognition and physical and perception abilities and decrease distressed behaviours (Zeisel *et al.*, 2003; Fleming and Purandare, 2010). Making the care home environment homelike is not just about therapeutic design choices – smaller-scale spaces, domestic material choices, or accessible fixtures and fittings – it is also about enabling people with dementia to have access to their personal belongings and to private and outdoor space (Falk *et al.*, 2013; Rijnaard *et al.*, 2016). For people with dementia, bringing personal belongings into bedrooms in care homes creates a meaningful bridge between the 'real home' and the care home, and facilitates a sense of attachment to the new place (Nygaard *et al.*, 2020). But for people with dementia, just like the rest of us, home does not just coalesce around the physical and material. Instead, people with dementia claim that feeling at home in care homes can be facilitated by meaningful relationships (Nygaard, 2020), meaningful activities (Rijnaard *et al.*, 2018) and real autonomy over both (Falk *et al.*, 2013).

Despite the evidence around homelike environments, for many people with dementia such environments in care homes are still elusive (Robinson *et al.*, 2010; Royal Commission into Aged Care Quality and Safety, 2019), with many residents experiencing declined agency and increased passivity (Davis *et al.*, 2009). This is particularly an issue in so-called ‘secure’ or ‘special’ dementia facilities that focus on restricting mobility, managing people with dementia’s distress and movement through locking doors (Steele *et al.*, 2019, 2020a, 2020b). These care settings are characterised as sterile and clinical (Kontos, 2015). Bedrooms, supposed sanctuaries of privacy, can be accessed at any time by staff and other residents (Villar *et al.*, 2014). In the study by Robinson *et al.* (2010), participants said their family members with dementia often tried to escape or begged to leave the special care unit in which they lived. The implication is that while the evidence points to the benefits of homelike environments in care homes, there is still some way to go in terms of existing care home facilities.

Existing research about a sense of home for people with dementia in care homes has tended to focus on how people with dementia feel at home in the care home itself (Nakrem *et al.*, 2013; Nygaard *et al.*, 2020). Given that many people with dementia experience an ambiguous sense of home in care homes, in this paper we ask what home means to them in a broader sense, drawing in important places and people in their lives, in ways that extend beyond the physical and material bounds of the dwelling. Our aim in asking this question was to explore how we could potentially incorporate some aspects of a broader sense of home – one that is able to account for physical space, but also relationships with others, routines, emotions, activities and sensory experiences – into the care home. Our emphasis then was not on the literal home, but on the meaning or sense of home for people. To arrive at this broader sense of home, the study design used an arts-based method, body mapping, to focus on the intersection between embodiment and the home, as a way of drawing connections between home and selfhood (Kontos, 2015). In the following section, we trace how literature from human geography, sociology and ageing studies has explored the relationship between embodiment and the home. By situating our empirical case study within this body of work, we hope to expand how meaning is given to ideas of home within care settings, but also contribute to cross-disciplinary understandings of the home more broadly.

Embodiment and the home

In his paper on the meaning of home for people with physical disabilities, Imrie (2004: 745) argues that a ‘person’s feelings about, and experiences of, home cannot be dissociated from their corporality of the organic matter and the material of the body’. In other words, experiences of home are always embodied. This perspective is inherently phenomenological, paying attention to how home is produced and given meaning through interactions between body and space (Imrie, 2004). As Merleau-Ponty (1962: 273) explained, the ‘body is the fabric into which all objects are woven, and it is, at least in relation to the perceived world, the general instrument of [my] “comprehension”’. In dementia studies, embodiment has also become an important lens for understanding a person with dementia’s ongoing sense of self (Kontos, 2004, 2005). With the body both our most intimate home

(Smith, 2013) and the way we experience our material homes (Merleau-Ponty, 1968), it is important to understand the ways in which home is produced, experienced by and felt for people with dementia.

In this section, we explore four central ways experiences of home are embodied by people, including people with dementia: (a) as a place for things our bodies need, which may include physical objects, but also a means of caring for our bodies (Tolia-Kelly, 2004; Blunt, 2005; Gorman-Murray, 2008; Ralph and Staeheli, 2011; Sandberg, 2018); (b) as a site of important and intimate relationships (Aminzadeh *et al.*, 2010; Ralph and Staeheli, 2011; Pilkey, 2013; Wiles *et al.*, 2017; Fæø *et al.*, 2019); (c) as a place for us to ‘do’ routines of selfhood (Bowlby *et al.*, 1997; Angus *et al.*, 2005; Dyck *et al.*, 2005; Blunt and Dowling, 2006; Davis *et al.*, 2009); and (d) through being places of sensory experience (Angus *et al.*, 2005; Duffy and Waitt, 2013).

Homes hold meaningful things to help people embody their sense of selfhood. Human geographers highlight the role of domestic materiality in creating ‘home’ (Tolia-Kelly, 2004; Blunt, 2005). Our bodies use objects and things to make the home more representative of the self, including aspects of culture, gender, sexuality, spirituality and beliefs (Blunt and Dowling, 2006; Gorman-Murray, 2008; Ralph and Staeheli, 2011; Sandberg, 2018). This extends to the ways in which the home enables people to care for their bodies, through washing, grooming, dressing and preparing for ‘public’ life (Imrie, 2004). The implication is that the processes of making homes and identities are deeply entwined, in ways that might be challenging in care home settings.

Twigg and Buse (2013: 326) show how when people with dementia move into care homes they use clothes as a kind of *home on the body*: ‘clothing can be significant as part of the “environment closest in”, the immediate physical surroundings of the body’ (Buse and Twigg, 2014: 15). For people with dementia clothes become a ‘materialisation[s] of memories’ and the wearing of clothes as ‘central to how [people] perform [their] identities’ (Buse and Twigg, 2015: 1). Indeed, sentimental objects in general are thought to be especially important for people with dementia to feel at home when moving into care homes (Aminzadeh *et al.*, 2010; Buse and Twigg, 2014). Household and familiar objects can make people more comfortable when they move into care homes: ‘they identify with ... things that they know and if you can give them that then they’re not in a whole different place’ (Davison *et al.*, 2019: 3906). By contrast, being surrounded by objects designed for use in health care can evoke the opposite sensation – these objects are not decorative, nor sentimental or familiar, and do not elicit a sense of home (Angus *et al.*, 2005).

The meaning of home is also fundamentally associated with the relationships enacted there (Aminzadeh *et al.*, 2010; Ralph and Staeheli, 2011; Pilkey, 2013; Wiles *et al.*, 2017; Fæø *et al.*, 2019); our embodied experiences and feelings about home are yoked to our interactions with other people’s bodies in the space. Ratnam (2018) and Wiles *et al.* (2017) argue, however, that relationships associated with home can extend well beyond those living in the immediate physical dwelling, to include neighbours, community members and other networks. Adding further complexity, Penfold *et al.* (2020) critique white, Western-centric notions of home as a physical dwelling, and the foregrounding of human relationships as the primary aspect of home. For the Aboriginal community members with

whom they worked, home was found in their relationship to Country and the ‘ancestors, people, animals, rocks and plants’ that this comprised, which was ‘felt and known through the body’ (Penfold *et al.*, 2020: 1527). Home was fluid, embodied and clearly related not just to people, but to places and things that lay beyond physical residences (Penfold *et al.*, 2020).

In Fæø *et al.* (2019), participants with dementia saw their homes as an expression of the lives they had built with their partners. The relational aspect of home had added potency for a participant whose husband had died – the physical home was associated with their shared history, and as such, his presence could still be felt there (Fæø *et al.*, 2019). In Aminzadeh *et al.* (2010), participants demonstrated strong attachments with the things they associated with home as they prepared to move into residential aged care. This included the relationships enacted in and around the home, which participants worried would become lost (Aminzadeh *et al.*, 2010). If home is where we connect with friends and family, finding ‘home’ in care settings – in the absence of these people – is difficult to imagine. An approach attuned to embodiment and the home opens up an opportunity to understand how relationships (that extend beyond the material home) shape meanings of home for people with dementia.

Home is also constituted by what we do with our bodies there and why (Bowlby *et al.*, 1997; Blunt and Dowling, 2006). Embodied routines give homes meaning. While most research focuses on activities *within* the physical home (Angus *et al.*, 2005; Dyck *et al.*, 2005; Davis *et al.*, 2009; Robinson *et al.*, 2010; Fæø *et al.*, 2019), the routine and embodied ‘doing’ of home also occurs outside. In the study by Dyck *et al.* (2005: 179), people receiving long-term care made themselves at home through ‘boundary maintenance’, seeking to renegotiate control over their increasingly medicalised surroundings. ‘Julia’, for instance, used her bed as a ‘control station’: ‘the positioning of the bed in front of her doorway enabled her to see into the living area ... and allowed her voice to carry through the doorway to reach [the worker]...’ (Dyck *et al.*, 2005: 180). Thus, Dyck *et al.* (2005) frame what people do with their bodies as ways of making and remaking home. This approach highlights the ongoing production of home through action, lending valuable insights into how the meaning of home might be brought into the care home setting.

For people with dementia, the importance of ‘doing’ home is evident through their distress when these routine doings are interrupted (Fæø *et al.*, 2019). There is increasing focus on ensuring that the design of care homes and care models themselves support people with dementia to *do* homelike activities (Davis *et al.*, 2009; Fleming *et al.*, 2015), rather than traditional designs which focused on functionality for staff. However, as the support needs of people with dementia increase, doing the routines of home with their body also requires more support. O’Sullivan and Hocking (2013) found that for people with dementia living in the community, opportunities to engage in day-to-day activities declined as their support needs increased, even though their desire for meaningful activity – both inside and outside the physical home – remained. Du Toit *et al.* (2019: 578) identified the same need within care homes, defining a lack of meaningful tasks and engagement as ‘occupational deprivation, alienation and marginalisation’. The implication is that a broader view of home creates an opportunity to identify routines that may have extended beyond the physical and material bounds of a dwelling, and which can be incorporated into care home routines in meaningful ways for people with dementia.

Finally, sensory experiences are central to how people experience home with their bodies (Angus *et al.*, 2005; Duffy and Waitt, 2013; Ratnam, 2018). Angus *et al.* (2005) identified that for some of their participants, home partly lay in what they could see, hear, feel, taste and smell. In Duffy and Waitt's (2013) research involving people who migrated to a small coastal town in Australia, participants depicted home as a culmination of ambient noises that ranged from the idyllic – the ocean, rainfall – to the more mundane – a boat engine, the hum of a fridge. Listening to these sounds is an inherently embodied act: 'We experience sound around, in and through our bodies ... reminding us how place and people are very much intertwined' (Duffy, 2015: 8). This work not only demonstrates the importance of a sensory approach in understanding how meaning is given to the home, but also extends the conceptual and geographical bounds of the home, to incorporate a broader sense of place and landscape.

Sensory interventions are found to benefit people with dementia (Haigh and Mytton, 2016; Collins *et al.*, 2020; Lorusso *et al.*, 2020; Smith and D'Amico, 2020; Tischler and Clapp, 2020). Tischler and Clapp (2020) particularly when they incorporate the backgrounds and preferences of each person (Lorusso *et al.*, 2020). However, most of the studies lack a person-centred approach; they might adjust for what people like and do not like but not tailor sensory experiences to the past or the home (Haigh and Mytton, 2016).

Despite the importance of a sense of home to identity, belonging and quality of life for people with dementia in care homes, empirical work at the intersection of home and embodiment is currently limited. This is especially problematic given how common and disruptive the process of relocating into residential care is for this group. The expanded view of home outlined above has brought literature in human geography and sociology into conversation with work in ageing studies and dementia care. In what follows, we attempt to contribute further to this conversation, drawing on a research project led by LS and CC, conducted with older people living with dementia and/or cognitive impairment in a care home setting. We begin with a Methods section outlining the study design, recruitment and process of data collection, which used the arts-based method of body mapping to explore notions of home. This is followed by an exploration of findings, and a Discussion section looking at the implications of the work for how an expanded view of home might be incorporated into the care home for people with dementia.

Methods

Design

This study was conducted in the context of a larger Participatory Action Research (PAR) project, which aimed to support connections for people with dementia living in a care home that was moving from one location to another (*see* Smith and Phillipson, 2021, 2022; Smith *et al.*, 2023). In Australia, care homes are commonly referred to as residential aged care but in this paper we will use the internationally accepted term 'care homes'. PAR projects usually cycle through three stages: (a) observing and planning, (b) acting, and (c) observing and reflecting (Bradbury and Reason, 2003). In the first stage of the study, we found that residents with dementia (diagnosed or suspected) often wanted to go home, with the care home containing very few

personal objects or reminders of what home meant for them. In response to this, the second stage involved supporting families, allies and people with dementia and/or cognitive impairment themselves to create memory boxes and other objects of personal value (Smith and Phillipson, 2021). Two workshops were conducted that explored what home meant to residents. Participants were prompted to reflect on what the resident's body felt and experienced when it was at home – where their feet rested, what they held in their hands, what they could see and hear, what was inside different parts of their body (brain, gut, lungs) and what was going on around them.

While initially these workshops were designed for family members and care partners, people with dementia themselves wanted to be involved. The study design changed to accommodate this, with talk-based focus groups becoming arts-based ones. Body mapping was chosen for conceptual and methodological reasons. Body mapping allows people to map the home closest in (their body), and to show how this interacts with their feelings and experiences in the environment. Body maps increase participation among people with cognitive impairment (Dew *et al.*, 2018), and allow people to explore embodied selfhood, sensory experiences and routines in multi-modal ways (Smith and Dowse, 2019). Conducting body mapping in a group has also been found to foster comfort, community and new kinds of collective knowledge (Chenhall *et al.*, 2013; Notara and Robinson, 2013; Smith and Senior, 2020).

Recruitment and consent

This study was conducted in one care home in a small coastal town in New South Wales, Australia. The facility's management advertised the workshops to families and care partners by placing a flyer in an email, newsletter and around the facility. Interested family members contacted the research team directly by email or phone, after which the researchers discussed the project with them and sent Participant Information Statements and Consent Forms.

At the time of advertising the workshops, the researchers had already been conducting research at the facility for over six months, engaging over 40 family members and people with dementia and/or cognitive impairment. Because the flyer included a photograph of LS, residents approached her independently. With an amendment to the initial Ethics and Study Design, we expanded the workshops to include people with dementia (diagnosed or suspected). Easy Read Participant Information Sheets and Consent Forms were created to enable the informed consent of people with cognitive impairment. LS, who had experience conducting research with such groups, talked through the consent process, and conducted an Evaluation to Sign Consent Measure (ESCM) (Resnick *et al.*, 2007). If the ESCM could not be completed, a family member or care partner signed consent by proxy, and approaches of process consent (Dewing, 2008) were followed.

Data collection

Each workshop was facilitated by LS, with two other researchers (including CC) acting as key supporters for participants. While some of the people with dementia knew one another by sight, the family members had never met. This was in part because half of the participants who chose to partake were new to the facility. As such, the first 20 minutes of the workshop focused on introductions, including

the role of the researchers. The workshops were held in the dining room of the existing care home, which was particularly familiar to the residents. Cake, tea and coffee were provided. Each workshop lasted for one and a half hours, and involved building a body map around the broad question of ‘What makes you/OR the resident that you support feel at home?’

Participants co-created body maps that centred on the resident’s experience of home. In most cases, the body map was co-created by a triad: the person with dementia, their family member/care partner/ally and a researcher. In three cases, however, the person with dementia was absent because their family member decided that the degree of their cognitive impairment was too significant to be involved in the process. In these three cases, the family member and a researcher co-created the map. These maps were much more detailed than those co-created with people with dementia, where the emphasis was on supporting their expression. Both people with dementia and family members emphasised that doing the map helped them think about themselves or the person with dementia differently, remembering versions of the self they had forgotten.

Each body-mapping group was given a template of a body printed on an A3 piece of paper. While body maps are usually produced on large body-sized pieces of paper (Boydell, 2021), A3 templates were used to accommodate the physical frailty of older participants and the practicalities of a small space and short time. Art materials such as felt markers, pens, glitter, stickers, magazines and different coloured paper were laid out to support the creation of the maps. LS and CC had also created sample body maps based on their own reflections of what home meant for their own grandparents (one of whom has dementia). These sample body maps were used to help introduce body mapping to participants, to demystify the art making (neither were sophisticated), and to make instructions multimodal and accessible for those with cognitive impairment.

The workshops used the body map as a strong scaffold to guide conversations with participants. The facilitator started with the feet (‘Where are your feet when you feel most at home?’) and then moved to the eyes (‘When you’re at home, what do you see?’). Other prompts asked participants to consider, when they are at home, what is: in their heart, head, ears, hand and stomach; on and under their skin; and what is nearby. With the participants’ permission, non-identifying photographs were taken of the workshop and of the body maps. Field notes were created after each workshop by each researcher to record the meaning of the body map and the process of making it.

Participants

Because of the way the study evolved, the participants included residents with dementia (diagnosed or suspected) (four), family members (five) and one volunteer who knew the participant she was supporting. Seven body maps were created in total, four being created by people with dementia and their supporters, and three created by a family member. All of the study’s participants were women, although two body maps were created by family members about men with dementia and complex support needs who were not present at the workshop. All of the residents were more than 80 years old. Five of the seven body maps created were about

people with dementia who had been in the care home for less than a year, and three for less than six months. One of the residents had lived in the care home for over five years. Pseudonyms are used in this paper.

Data analysis

Data analysis of body maps involves analysing and synthesising both visual data (photographs and body maps) and textual data (a key for each body map and field notes) (Bagnoli, 2009; Dew *et al.*, 2018). Smith and Dowse (2019) and Dew *et al.* (2018) describe how capturing this complexity is best done through narrative. As such, the first phase of analysis drew on narrative inquiry to capture the multiple and overlapping stories going on in the data. Through creating stories about the participants, narrative inquiry is useful in representing lived (and research) experiences, so that the 'sensory, embodied and living conditions of existence can be foregrounded' (McMahon and McGannon, 2016: 98). Narratives, field notes and body maps were analysed using thematic analysis and constant comparison (Braun and Clarke, 2006). Iterative discussions between authors clarified themes, deleted redundancies and created connections between themes. This process was repeated three times until the final themes and subthemes were agreed upon. 'Home as embodied' created an overarching theme, while 'Embodied objects', 'Home as relational', 'Home as doing' and 'Home as sensing' became subthemes.

Findings

Objects for making oneself at home: clothes, jewels and tools of the trade

The participants chose to put clothes on the bodies in each of the body maps, whether they were drawing on behalf of someone they knew or were a resident at the care home (Figure 1). Judy, who was assisted by a volunteer to put her map together, wanted to add the beaded jewellery around her neck personally. 'I'm a terror for jewellery', she told her volunteer and the researcher who was working with her (field notes, LS, 29 October 2019). This was the first thing Judy drew. Her handbag was also drawn on the map, slung around her shoulder. Inside this handbag was a selection of smaller objects: a manicure set, tissues, chips, glasses, makeup and more jewellery, among other items. Most of these were related to physical appearance, or rather, her ability to manage and negotiate that appearance. Field notes describe Judy's apparent joy when telling the research team about the items in her real handbag (field notes, LP, 29 October 2019). A similar theme emerged during Beverly's body-mapping session:

She was so neat and well groomed, makeup on ... I asked if that was important to her, her clothes and appearances. She said it was very important ... We talked about what would be in the handbag and how important that [was]. (Field notes, LS, 22 October 2019)

For both of these women, their clothes and accessories were depicted as a way of feeling at home in the present.

For Mary and Edward, neither of whom were present for the body mapping, clothing was also a prominent motif, albeit in different ways. Mary's daughter



Figure 1. Doing body mapping together.

described her as an impeccable dresser who loved to wear bright clothes – as such, she depicted her wearing a carefully co-ordinated outfit, with red nail polish to match her red bag and shoes. Her perfectly presented hair alluded to her background as a hairdresser. Edward was drawn standing on the lawn of his family home, in his blue terry towelling hat, which his family said he always wore whenever he was outside. Edward was characterised as an outdoors man as the body mapping progressed. Although Mary's and Edward's style were disparate, both maps used clothing to show continuity and a connection to their personal histories. Unlike the body maps of Judy and Beverly, who took pains to represent what was important about what they wore now, Mary's and Edward's maps were drawn by their family members without their input and seemed more focused on clothes they used to wear in the past.

Other clothing items associated with home were clearly related to a sense of comfort. When asked where they liked having their feet at home, Beverly and Joyce both immediately said they enjoyed wearing slippers and having their feet up. Beverly had a television drawn on her map, too, while Joyce was drawn lounging in a comfortable armchair and wearing tracksuit pants, as well as Velcro slippers that were easy to take on and off. Edward was drawn wearing a singlet, shorts and thongs, and even Mary (usually so impeccably dressed, we learned) was drawn with one shoe off because she liked to be barefoot. Even for participants who liked to dress up, home could also be a place of no pretence, where people could be at ease. These contrasting ideas about dress demonstrate the complex and ambivalent ways in people conceive of home, and how clothing can be central to a sense of homeliness.

Many objects on the participants' maps were important to them and their sense of home because of what they allowed them to do. They were afforded status

because they were associated with utility and ‘doing’ home, and by extension, with competency and activity. Arthur’s and Edward’s family members drew tools and equipment on their maps – for Edward, a measuring stick that he had used as a tradesperson, and for Arthur, a wrench, to show that he was ‘very into fixing and tinkering with things’ (field notes, CC, 22 October 2019). Although the tools on Edward and Arthur’s maps had been used in different contexts, both arguably served as a reflection of their competency; the things these men were good at. Similarly, Judy asked her supporter to sketch a brush in her hand to demonstrate her interest in painting and drawing, while a sewing needle was placed in the other.

Similarly, Ann’s map included a drawing of a Fabergé egg that she had beaded beautifully herself (Figure 2). Next to it, Ann’s daughter wrote ‘mum is very crafty’. Ann’s daughter had brought the real Fabergé egg to the workshop, along with some of her mother’s bowling badges encased in a frame, among other items associated with Ann’s ‘doing’ practices. Ann’s daughter had hoped that bringing the objects would support Ann to think about what she liked to do. Field notes comment on the reaction that Ann’s masterfully crafted items elicited: ‘when [she] got out all of [those] creations, we were astounded’ (field notes, CC, 22 October 2019). Prior to Ann’s daughter bringing out these objects, the field notes described that Ann had ‘looked and sounded unsure about the task and remained fairly quiet, letting her daughter talk for her’ (field notes, LP, 22 October 2019). When her daughter brought out the objects they supported her to engage. She ran her fingers over the objects for much of the workshop, opening and closing them, describing how she had made them and later showing the badges to one of the other older participants, who had also played bowls. For Ann’s daughter these objects, and the skills



Figure 2. Ann’s Fabergé egg.

and capacity they represented, seemed to represent part of her mother. At the same time, Ann's daughter also engaged with these items with a sense of melancholy that her mother could no longer make objects in the same ways that she used to, and that in the care home she did not have many options for doing: 'There was in her a sadness that her mum couldn't remember what she used to do or how to go about doing things anymore. She could still knit but needed to be reminded to go to knitting. She needed prompts' (field notes, LS, 22 October 2019).

Drawing the body in a home of the past: re-connecting with family and friendships

None of the participants drew their body at home in the care home, instead they drew their bodies as feeling at home in the past, in a different place and with different people to those who were in their present. For Judy, home was intricately tied to relationships with her parents and the location of the family home from her childhood. As part of her depiction of home on her body map, Judy used the space inside her head to place memories of things that her father and mother had done in and around the family home. For her mother, this was sewing and for her father this was building boats. They had lived by a large river, and Judy would take a boat every day to cross the river on her way to school. During the workshop, Judy used the symbol of her heart to reflect the people who loved her and who helped her to feel at home (Figure 3). The space directly inside the heart was reserved for her mother. A line can be seen connecting this heart to writing on the outside of her body, which reads 'lovely sisters ... youngest of 10...' Elsewhere on Judy's map, the words 'people, children and flowers' were written, with an arrow connecting them to her body.



Figure 3. Judy's body map.

Likewise, a narrative around relationships emerged gradually throughout Beverly's body-mapping process, as the researchers worked with her to draw out her story. When asked what she enjoyed looking at when she felt at home, Beverly initially said she liked watching television. Yet, after further conversation with the researcher team, Beverly began to speak more and more about the relationships that were important in her life. Not all of these involved other people – her Persian cat and her Pomeranian dog can be seen sitting by her feet on her body map. Her map also included an album of family photographs from when she was young, as well as her children – who are depicted inside a love heart in her chest – as well as other children whom she used to see playing in her neighbourhood.

This motif of significant relationships being written inside and around the heart, as described in Judy's and Beverly's maps, was repeated during the workshops, at the research team's prompting question, 'what's in your heart when you are at home?' Writing inside the heart seemed to be a way for the participants to show close relationships as inextricably linked to the meaning of home. During the body-mapping workshop they attended, Edward's family added a red heart with the words 'people person' inside, and 'likes to talk to people' written next to his mouth. Through the map and in conversation with one of the researchers, Edward's family explained how he loved to socialise – he had been part of his local Surf Life Saving Club, would often catch up with his neighbours and had enjoyed 'people watching' from his balcony. Joyce's map showed a similar theme. 'Loves her family' was written next to her heart, while her eyes were drawn as though they were looking at family photographs. 'I couldn't manage without them', she told the researchers during the body-mapping process (field notes, LP, 22 October 2019). Only Mary's map did not include a heart – perhaps so as not to ruin the carefully curated outfit she was drawn as wearing – but a speech bubble highlighted what Mary liked to talk about when she was at home: 'Chatty. Family ... Social' (Figure 4).

Two of the people whose bodies were mapped but who did not attend the workshops – Mary and Arthur – were married. Their daughter worked closely with a member of the research team to co-construct their body maps. Their relationship can be observed subtly on each of their maps: Arthur and Mary were both drawn with one foot on the sand, representing their shared, embodied experience of spending time at the beach (Figure 5). During the workshop, as a rapport developed with the researcher who was assisting her, Mary and Arthur's daughter elaborated on her parents' relationship and its recent history. They had been living together in low-needs care accommodation but had been separated when Mary's dementia required more support: 'They're all learning to cope with the new separation, though she is happy that in the new facility their rooms will be opposite each other' (field notes, CC, 22 October 2019). While their daughter was not explicit about why she did not include the husband and wife more overtly on the other's map, it is perhaps a reflection of this dislocation from one another in their current home, and their daughter's own attempts to reconcile with this.

One of the most poignant illustrations of home's relational nature was drawn on Joyce's body map. Joyce told the researchers about how she had lived next door to her friend Patricia for 53 years. When Joyce's husband passed away at a young age,



Figure 4. Mary's body map.

Patricia became her companion, tennis and lawn bowls partner, and confidante. Their children grew up together, passing through a gate in the fence from one house to the next. Although Patricia's name is written at the bottom-left corner



Figure 5. Arthur's body map.

of her map and might easily be overlooked, their relationship seemed to be at the root of what home meant for Joyce. Home *was* her relationship with Patricia. During her body-mapping session, Joyce explained that after Patricia passed away,

her own health declined. She was admitted to hospital and did not return. 'Without [Patricia], she didn't know how to live there anymore' (field notes, LS, 22 October 2019). Home was no longer home without the relationship that defined it.

Doing home by enjoying the body: playing sports and games, leaving the house, being free

Participants talked about 'doing' leisure activities as a way of 'doing home'. This was shown in more overt and conventional ways on some maps than others. For example, the items surrounding Mary's body included mahjong tiles, board games, watching game shows, DVDs, lawn bowls and a tennis racquet. Ann's map was similarly rich with symbols of play, including: puzzles, bingo, a book for reading and domino pieces (Figure 6). These activities highlight how the notion of home extends beyond a container for everyday life, to support the pursuit of personal interests that often take place beyond its normative boundaries.

Many of the practices that people wanted to put on the body maps – the 'doing' of home – were not activities that had been done inside physical houses at all. Certainly, Judy's depiction of herself by the river is indicative of this. Time spent playing lawn bowls for Ann and Joyce, or playing tennis for Beverly and Joyce, seemed to be associated not just with recreation but with pride in the excellence they had demonstrated as younger women. Sporting activities were also well-represented on Edward's body map, which included a football and a golf club. Clearly, home and the 'doing' of home was not limited to four walls and a roof. Ann, Joyce and Beverly all felt they could no longer play sports – at least not in the way they wanted to, with that same excellence – given that they were now using walkers. 'I wish I could still be active', Joyce reflected (field notes, LS, 22 October 2019). Importantly, Ann's, Joyce's and Beverly's feelings about not wanting to play bowls or tennis should not be interpreted as a loss of desire for meaningful activities. Ann's daughter said she was concerned that this was lacking at the care home where her mother lived: '[Ann's daughter] really stressed how active and busy her mum had been and that there really wasn't enough for her to do that was meaningful and supported' (field notes, LS, 22 October 2019).

Although Beverly initially asked that she be drawn at home in a garden chair and that she be watching television, her body-mapping session increasingly revealed how active she had been both in the home and outside it. Field notes observe how a drawing of Beverly sitting down did not seem to capture aptly many of the things that were actually important to her about being home, not least her mobility beyond the home:

It became clear that [she] really valued being active and free in movement ... She'd always walked around the suburb where she lived, walked to the shops and along the beach. It was very important that she could get places. (Field notes, LS, 22 October 2019)

Later in the day, when the researcher raised the topic of car keys, Beverly explained how she had loved driving 'with surprising ferventness' – she revealed that she would 'go everywhere in her car, until she had falls and they took her license away' (field notes, LS, 22 October 2019). Joyce, too, mentioned how



Figure 6. Ann's body map.

much she valued being able to leave her home. Her map detailed how she 'loved] going on the bus, going out for lunch' and swimming at the beach when she had been younger. Edward's map featured a car that he had fastidiously cleaned and that

could be taken wherever Edward wished; a travelling home. Thus, for many of the participants, the sensation of being at home meant having the ability to leave it, and return when they pleased. Perhaps this is also why Edward was drawn with a wallet in his pocket on his body map, and why Mary was drawn with a purse. These are tools to be used for engaging with the outside world and, like Edward's car, for exercising autonomy. Given that home is depicted in the literature as a space of personal control (Dyck *et al.*, 2005), it is perhaps fitting that objects such as car keys and wallets appeared on the participants' maps. None of the participants mapped aspects of the care home itself. This has implications in a care setting, where mobility beyond the 'home' is usually restricted.

Sensory dimensions of home: landscapes and soundscapes as home

The outdoors, and the sights, sounds and textural experiences associated with them, featured prominently on participants' body maps. This frequently derived from the broader landscapes participants inhabited prior to their transition into the care home. For Judy, this meant the place she had called home as a child. Judy wanted to situate her body on the map within the natural landscape where she grew up. Being drawn in the outback and not in the city was, according to field notes, 'really important to Judy, and she repeated it a number of times' (field notes, LS, 29 October 2019). Judy instructed the researcher to draw the huge trees and make them as big as the page. The tree took up the entire left side of the map – Judy herself drew her name on it, just as she had carved her name into the real tree from her girlhood. Field notes reflected that Judy, who had been withdrawn during the workshop, began laughing and smiling as she recalled her family home, demonstrating a strong connection to place (field notes, LP, 29 October 2019). The water was drawn beneath Judy's feet to show that this was where she felt truly at home.

For Beverly, too, it seemed that being outside her house provided a greater sense of home than being inside it. She had been an avid gardener, but also enjoyed simply *being* in the garden, admiring the trees and flowers around her. She depicted herself as such, sitting on her garden bench under a great red sun (Figure 7). Like Beverly, Edward was also drawn in the yard, where he had spent much of his time when he still lived in his family home. Conversation with his wife and daughter illustrated how the lawn was one of the most precious parts of being home for Edward – his feet were drawn sinking into the grass. Edward's family told the researchers about how he mowed his lawn up to three times a week, and about how he spent most of his time outside in his blue terry towelling hat, watching over his lawn as people passed by. 'There was a close sense of connection with the environment directly around him ... he loved ... seeing the change in the weather and the water', the field notes explain (field notes, LS, 29 October 2019). The researcher adds how jarring it must be now that Edward is 'always inside now and does not have his grass to be proud of...' (field notes, LS, 29 October 2019).

Sensations associated with being outdoors sat alongside other immersive sensory experiences on the body maps, including listening to music. Arthur's daughter mentioned that he had loved spending time at the beach – Arthur was drawn with his toes in the sand on one foot. His other foot was shown tapping to music by Frank Sinatra, one of his favourite crooners. A line of musical notes

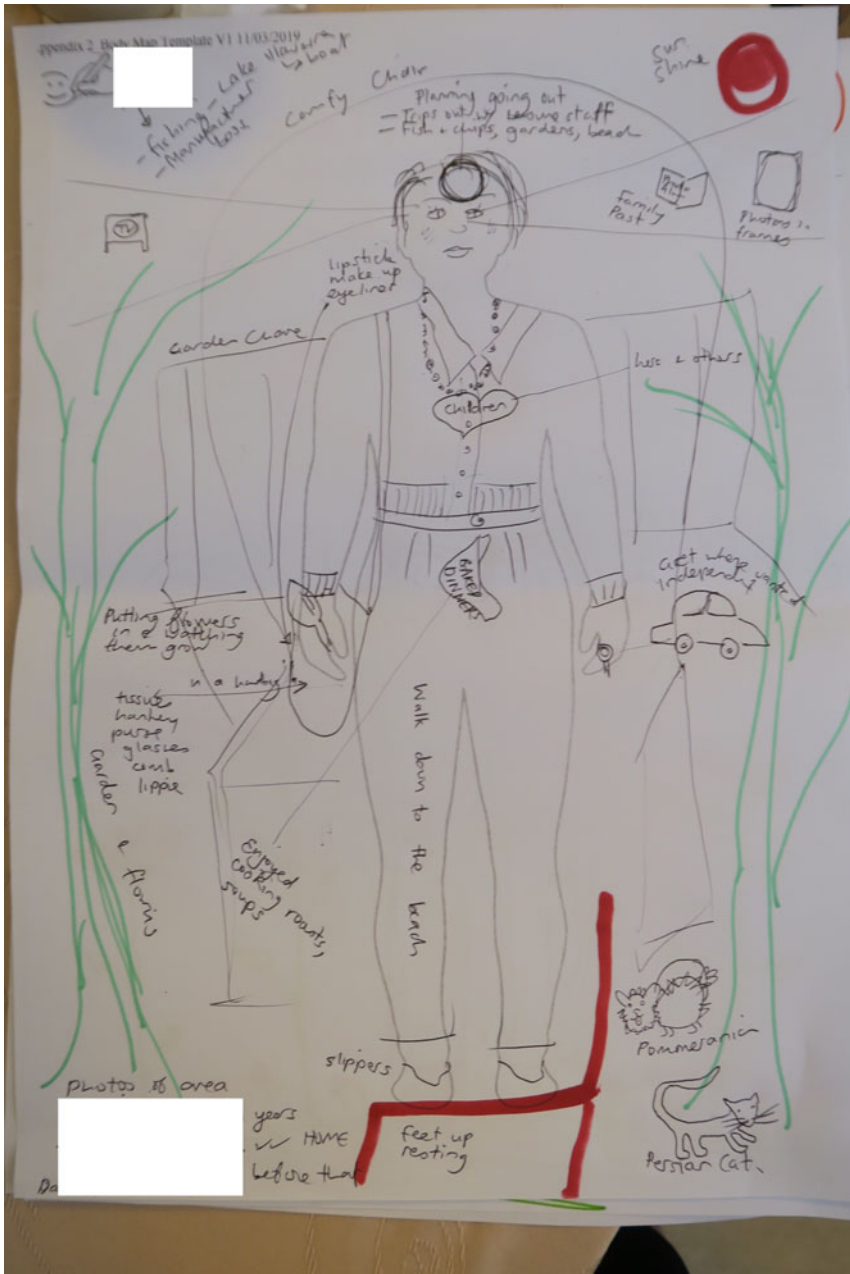


Figure 7. Beverly's body map.

was drawn next to his mouth and ears to show Arthur singing along. Music notes also appeared on Edward's map to show him listening to country music, and on Mary's to represent her love of stage musicals.

Taste was another common sensory thread in the body-mapping sessions. Beverly's and Ann's maps both show a baked dinner in their stomachs. In Beverly's case, this sparked conversation about how she had loved the activity of cooking roast dinners, and how these meals were thus associated with a sense of personal satisfaction for several reasons. For Ann, the experience of eating a baked dinner triggered memories of times when she had enjoyed them at home. Food was also an important component of Edward's map, which was decorated with ice cream, fish and chips, tea and custard tarts among more of his favourite treats. His family spoke particularly fondly about foods with a relational aspect. Sharing beers over a barbeque with his neighbours – *connecting* over food – appeared to feel like home to him. The implications of this for Edward, and for the other participants living in a locked care home, will now be considered in the Discussion section.

Discussion

For the participants in this study, home was extremely important, but home was not where they lived in the care home. Instead, home was elsewhere; somewhere they had left behind (Davison *et al.*, 2019). Home was not a house – a static place – but was instead something that people *did* with and through their bodies (Bowlby *et al.*, 1997). This extends Kontos' (2004) conceptualisation of the importance of embodied selfhood for people with dementia, where knowing and self are embedded in the body. In this study, we recognise how embodiment of selfhood is tied to home and therefore uniquely spatial. The embodied self at home is not housed in bricks and mortar – instead, embodied experiences of home for people with dementia involve intimate routine exchanges and processes, and patterns of movement with objects, people and places. As such, supporting people with dementia to engage reflexively with their sense of home will, arguably, support their embodied selfhood as well. If the 'body is the fabric into which all objects are woven' (Merleau-Ponty, 1962: 273), the home becomes a loom; a frame for holding taught the threads, a structure to allow new fabric to appear. This understanding of home as embodied helps to inform how care homes might support people with dementia to feel more at home. In this Discussion section we will step through the ways in which this paper challenges current ideas about home for people with dementia, and consider how each of these might inform care.

Firstly, for people with dementia in this study, home was associated with freedom of and with their bodies; it is having the autonomy and mobility (Dyck *et al.*, 2005) to set out and head home again. The focus on symbols of freedom and autonomy of movement in the body maps (keys, cars, wallets, handbags, walking and sporting bodies) is in direct contrast to the images often associated with care homes – fences, locks, supervision, clinical sterility (Kontos, 2015; Steele *et al.*, 2020a, 2020b). We wondered whether the participants' emphasis on freedom was in fact because this was what they most missed now – what they understood as significant to home in its absence. But this focus on freedom meant that home became expansive. It encompassed a broad range of relationships, activities and senses, which spanned across times and places. Unlike many previous studies of home involving people with dementia, which have predominately framed home

as associated with what we do inside (Angus *et al.*, 2005; Dyck *et al.*, 2005; Fæø *et al.*, 2019), in this study home was entangled with what occurred outside the home, in neighbourhoods, communities and nature. This is consistent with more recent studies of the perceptions of community-dwelling people with dementia who also articulate an integrated view of the people, places and networks that are needed to help them feel at home and included in their communities (Crampton and Eley, 2013; Smith *et al.*, 2016; Ward *et al.*, 2018).

If home involves the practices of going out and heading home again, there needs to be greater focus placed on not only supporting people with dementia and/or cognitive impairment to participate in regular household activities (Davis *et al.*, 2009), but also on the exteriority of 'doing' home beyond the care home, connected to residents' pasts and linked with current neighbourhoods and communities. While the Dementia Friendly Community movement has focused on making neighbourhoods and communities more inclusive and accessible for people with dementia (Alzheimer's Disease International, 2016), there needs to be more emphasis on how this can bridge the significant gap between life for people in care homes and their previous relationships with neighbourhoods and communities. Ward *et al.* (2022: 5) talk about this requiring a 'capacity-oriented' approach to understanding dementia and place, where ideas about what neighbourhoods and community need to be made and remade with people with dementia.

The second key point is that for people with dementia, home was embodied through connections to useful and familiar objects, like clothes and accessories, and sensations from their past. In other body-mapping research (Smith & Dowse, 2019), the body is rarely fully clothed, and the inside of the body is usually reserved for things that participants feel most strongly about – what lies in their minds, in their hearts, in their guts. In this study, however, the participants chose to fully clothe their bodies on their maps. In line with the argument put forward by Buse and Twigg, items of clothing are meaning-laden objects that facilitate the curation of identities for people with dementia and/or cognitive impairment (Twigg and Buse, 2013; Buse and Twigg, 2015, 2018). Interestingly, too, the maps that were drawn by people with dementia themselves were unique in this study. Rather than representing home as a collection of things from the past, these participants all drew the clothes and accessories they wanted to wear in the present, in care homes. Clothes and accessories, then, are perhaps the last embodiment of home for a person with dementia and/or cognitive impairment in care homes: the home 'closest in' (Buse and Twigg, 2014: 15).

Much like the clothes and accessories depicted and talked about in this study, other objects drawn or described in the body-mapping workshops were 'materialisation[s] of memories' (Twigg and Buse, 2013: 326) of home. Importantly, in addition to the sentimental objects usually associated with home (such as family photographs and medals), some of the objects associated with home were more utilitarian, related to *doing* practices (making, mending, crafting or playing). In her conceptualisation of embodied selfhood, Kontos (2004, 2005) drew on Bourdieu's notion of habitus, where sociocultural learning occurs and is articulated through the body. In this study, objects on the participants' maps such as the wrench and a measuring tool perhaps reflect the strong industrial and mining

legacy of the area where the research took place, and the cultures of these workplaces, which extend into the home (Wacquant, 2013; Carr, 2017). Other objects reflected more female-dominated crafting and sporting cultures (knitting needles, tennis rackets, bowls). Together, these objects highlight the importance of doing – and artefacts that support doing practices – in helping people with dementia and/or cognitive impairment to feel at home. They also illustrate how some objects, particularly those associated with industrial culture, are more crucial to recreating ‘home’ than is usually realised in care settings, meaning that this element of ‘home’ is seldom incorporated into care.

How do we ensure that people with dementia bring meaningful objects with them into care homes? This means not only the objects that celebrate their achievements (medals, family photographs, awards), but objects that allow them to connect with the embodiment of familiar routines and daily cultures of home and prompt the ‘doing’ of remembering. The familiarity of such objects can interrupt the clinical nature of health-care objects (Angus *et al.*, 2005; Davison *et al.*, 2019). However, in planning person-centred admission into care homes, there needs to be creative ways of identifying everyday taken-for-granted objects that offer crucial sensory reminders of home. The process of body mapping provided one way of structuring this conversation and identifying objects with care partners and people with dementia and/or cognitive impairment. It allowed participants to locate what was important to the person with dementia and/or cognitive impairment’s sense of home in ways that demanded immediate attention to the body, not in the kind of ways in which usual care planning often takes place.

The third and perhaps stickiest point in terms of care homes is that home is deeply relational for people with dementia and/or cognitive impairment, just as it is for us all (Ralph and Staeheli, 2011; Pilkey, 2013; Gorman-Murray, 2015; Okafor, 2018). Relationships are at the heart of the home, and were literally represented in the hearts of participants’ body maps. While participants represented family and partners as important, it was also connections and relationships with neighbours and other community members from the past that defined ‘home’. Relationships to pets and places were also of great importance (Penfold *et al.*, 2020). Rarely does someone bring these relationships with them into care homes, and even if one does enter care with a spouse – as Julie and Arthur’s example illustrates – these relationships rarely stay the same thereafter. This is a key point for several reasons. Firstly, if home means being around loved ones, then the absence of those people in care homes may prompt feelings of grief and loss, for which individuals with dementia and/or cognitive impairment require support. Secondly, the relational nature of home means that there is a need, and an opportunity, for care homes to change. Specifically, models of care that focus on fostering relationships – among care home residents, and between people with dementia and/or cognitive impairment and staff – could potentially facilitate a greater, and much needed, sense of home in these settings.

Strengths and limitations

Body mapping in this project facilitated an exploration of home that captures a holistic sense of home that may not have been possible with more traditional methods.

The creation of body maps with people with dementia was facilitated by collaboration with care partners and/or researchers. As discussed, this was a generative process which required the care partners and researchers using their existing knowledge of the person, the objects they brought in and expanding on glimmers of interest. This collaborative and relational aspect is in itself worth studying but is also a potential limitation of the study, as potential directions pursued in the collaboration were generated by both parties, rather than solely the person with dementia. That said, without this support, people with dementia would not be able to be involved in the research process at all, so the arts-based method facilitated a practice-based engagement that supported inclusion.

Conclusion

In this study, the use of body mapping provided unique insights into how people with dementia embodied the feeling of being 'at home'. The results highlighted 'home' as something that was practised or 'done' through use of objects and participation in rituals, sensations, remembering and relationships. Feeling 'at home' was shown to be highly relational and contextual – sometimes experienced through a relationship with a physical dwelling, but also through relationships with others, or through sensory experiences. The study highlighted the barriers to 'doing home' in care homes, and pointed to a number of ways a sense of home might be more creatively fostered.

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